

Cancer Inpatient Distress in First 48 Hours of Admission: Comparison of Distress  
Scores to Perceived Health Status

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### **Abstract**

Distress related to cancer diagnoses and treatment is prevalent in oncology patients. Distress screening is not a common practice in oncology inpatient settings, although standards from the American College of Surgeon will require documented evidence of distress screening, assessment, intervention, and evaluation by 2015 for certification. Professionals are seeking the ideal distress instrument for use in their settings.

In this study, a cross sectional design compared the level of distress and perceived health status from cancer inpatients (N=150) sampled in the first 48 hours of admission at a university-based, National Cancer Institute-designated comprehensive cancer. This study utilized the distress thermometer and its 38-item problem list to identify the level and source of distress in oncology inpatients with a variety of cancer diagnoses. Distress was elevated ( $M=5.8$ ,  $SD=2.7$ ) which is described as moderate to high distress. Six of seven subscales of the distress thermometer problem list indicated significant results ( $p<0.03$ ) with the exception of the practical subscale ( $p=0.23$ ).

Analyses of various demographic items identified a potential association between self-reported level of distress and perceived health status e.g. poor ( $n=46$ ), fair ( $n=54$ ), good ( $n=42$ ), or excellent ( $n=3$ ), which was significant ( $p<0.03$ ) in five of seven measures of distress associated with the problem list. In a busy inpatient setting during admission procedures, the self reported level of distress *and* perceived health status may provide an approximation of the patient's distress and lead to expanded assessment and appropriate referrals as necessary. This approach may provide improved distress screening with minimum interference in admission procedures.

## Introduction

Nearly half of all adults with cancer experience significant stress (American College of Surgeons, Commission on Cancer, 2013 [ACOS, COC]). The Institute of Medicine (2006) report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* emphasized the importance of distress screening related to the delivery of quality cancer care. Research has shown that increased distress levels may cause delayed treatments and missed appointments, and may be associated with worsening symptoms (ACOS, COC, 2013; Wagner, 2013). The National Comprehensive Cancer Network (NCCN, 2013) emphasizes that distress should be monitored throughout all stages of the cancer trajectory in order to provide optimal care. This includes initial distress screening, assessment, interventions, and evaluation, with documentation and subsequent interval distress screening (Wagner, 2013).

The screening of distress can include self-reported data, directed questions, questionnaires, association with specific phrases, or observations by professionals, caregivers, or family members. Self-reported data enables the patient to convey their personal feelings of distress without discretionary judgment or connotation by others. These various approaches to screening are critical to accurate data as some patients may under-report their true level of distress secondary to denial, 'good patient' behavior, resistance to disclosure, or inability to admit a need for assistance. The self-reported rating of perceived health status may correlate with the patient's level of distress, and thus provide another method of distress screening. The potential use of this demographic variable to identify distress levels in cancer patients will be discussed in this paper.

## **Background**

Distress in cancer patients is an important concept to consider in providing holistic care (Petty, Lester, 2014). Distress is a psychological state associated with the challenges of cancer diagnoses and associated treatments due to physical symptoms, interpersonal challenges, psychological symptoms or issues, social situations, or existential concerns (Holland et al., 2013). Screening is essential with follow-up assessment, interventions, and evaluation (Wagner, 2013). Distress screening is not commonly performed despite reports of moderate to severe distress levels in persons with cancer (Holland et al., 2013; Petty, Lester, 2014). Prolonged distress can negatively affect quality of life (Lester et al., *in press*). Prolonged exposure to stress can have a negative effect on quality of life, and manifest a host of physical symptoms including altered immune conditions (Mundy-Bosse, Thornton, Yang, Andersen, Carson, 2011).

## **Distress Screening**

Distress screening in cancer patients will be required as a usual component of care by the American College of Surgeons (ACOS) and Commission on Cancer (COC) by 2015 (ACOS, COC, 2012). Institutions that provide care for hospitalized cancer patients and clinic outpatients are scrambling to choose their method of screening with subsequent implementation and documentation. An efficient method to evaluate cancer distress will be vital to the delivery of excellent care.

The Distress Thermometer (DT) is a reliable and valid instrument to screen the level and source of distress in cancer patients. The DT consists of a vertical image of a thermometer with a 0-10 rating scale (1=no distress, 10=excessive distress). The DT

includes a 38-item problem list with five subscales: practical (6 items), family (4 items), emotional (6 items), physical (21 items), and spiritual/religious (1 item) (Bogaarts et al., 2011; Holland et al., 2013). The problem list provides important information to identify the source(s) of distress which leads to additional assessment and interventions.

The use of an electronic or paper instrument may be prohibitive for some institutions, yet the screening of distress will still be required. Choosing items or using only segments of instruments to obtain distress data may produce less than optimal, valid results. The fragmentation of instruments will reduce validity overall, may alter the meaning of results, and produce insufficient data for analyses. Therefore, additional resources may be necessary to aid institutions in obtaining baseline distress information. Knowledge of a patient's level of distress is meaningful to begin dialogue and subsequent assessment. Self-reported perceived health status may provide information about a patient's level of distress.

### **Perceived Health Status**

A number of factors may be associated with self-reported perceived health status, including variables such as chronic illness (e.g. cancer, diabetes, hypertension), health behaviors of smoking, dietary intake, physical activity, or exercise (Baruth, Becofsky, Wilcox, Goodrich, 2014; Tonosaki, Ishikawa, 2014), and social determinants such as socioeconomic status, disparities, or health literacy (Toci et al., 2014). Racial and ethnic variations or discrimination may affect the manner in which persons perceive their health status (Baruth et al., 2014; Gibbons et al., 2014) and may lead to increased distress with negative health behaviors (e.g. anger, physical or substance abuse). Psychological stressors such as anxiety and depression can lead to a lower perceived

health status with functional limits and increased morbidity (Gibbons et al., 2014).

Increased anger may lead to substance use or abuse and affect overall ranking of mental and physical health status (Gibbons et al., 2014).

The number of psychological issues and the time point or occurrence of issues in the cancer trajectory may be cause for lower perceived health status and increased distress (Rissanen, Arving, Ahlgren, Cernvall, Nordin, 2014). The decline of self-rated health can result in a greater need for encouragement and emotional support (van Houtum et al., 2013). Persons with chronic illnesses must continually adapt to their changing needs which may trigger distress and emotional support issues (van Houtum et al., 2013).

A worsened health status or increased symptom severity can amplify levels of anxiety and depression (Lin et al., 2013). Feelings of uncertainty, common with cancer patients may negatively affect mood, and in turn affect symptom tolerance (Lin et al., 2013). The emotional responses to uncertainty, specifically anxiety and depression, are increased while patients are awaiting results (Lin et al., 2013) or dealing with the relentless cancer. Interventions for negative mood states or uncertainty may reduce a person's perceived symptom burden and increase quality of life (Lin et. al, 2013).

Elevated and prevalent distress has been reported in breast cancer outpatients with multiple physical, psychological, and social needs, and a path of worry, stress, and loss (Head et al., 2012). Increased distress occurs during diagnosis, treatment, and early follow-up periods in the cancer trajectory (Agarwal et al., 2013; Head et al., 2012; Knobf et al., 2013; Luutonen, Vahlberg, Eloranta, Hyvari, Salminen, 2011).

Perceived health status may affect health-related quality of life in a positive or negative manner. Perceived health status may be interchanged, or considered as synonymous with health-related quality of life, although for purposes of this paper, perceived health status and health-related quality of life will be considered as independent terms or conditions.

### **Inpatient Distress**

Distress occurs in cancer patients admitted to the hospital, whether for a planned admission (e.g. for surgery or chemotherapy), or on an emergent basis. Few studies have examined inpatient distress (Clark, Rochon, Brethwaite, & Edmiston 2011; Goerling, Foerg, Sander, Scramm, & Schlag, 2011; Kligler et al., 2011). Intuitively one would expect increased distress and emotional issues secondary to the increased physical, psychological, and emotional acuity of hospitalized patients. Patients reported fatigue, drowsiness, insomnia, pain, and decreased appetite (Clark et al., 2011) on admission forms completed in the first 24 hours of stay. These symptoms were reported to interfere with work, general activities, and enjoyment of life (Clark et al., 2011).

### **Present Study**

The purpose of our study was to examine distress as associated with perceived health status in cancer inpatients during their first 48 hours of admission. Little is known about the level and sources of distress of inpatients during early admission and if the patients' levels of perceived health status have an effect on distress scores. The early admission time period is recognized as a stressful phase with fears of dying, recurrent disease, and bothersome symptoms. Therefore, these data are important to identify

priority needs in order to design interventions to decrease or prevent high levels of distress.

The primary aim of this study was to examine and compare the mean scores of self-reported distress levels and perceived health status among newly-admitted oncology patients. Seven measures of distress were used: the Distress Thermometer (DT) score, 38-item total problem list score, and five subscale scores, e.g. practical, family, emotional, physical, and spiritual/religion. Patients in a comprehensive cancer hospital with a variety of cancer types completed surveys in the first 48 hours of admission to provide data about their level of distress as associated with perceived health status.

## **Subjects and Methods**

### **Research Design**

A cross sectional design compared the level of distress and perceived health status from cancer inpatients (N=150) sampled in the first 48 hours of admission, including male (n=76) and female (n=74) patients.

### **Participants and Procedures**

**Accrual:** Patients were accrued from March 2012 to September 2012 from the medical and surgical oncology inpatient hospital settings. The setting was a large, university-based, National Cancer Institute-designated comprehensive cancer center. The study was approved by the university Cancer Institutional Review Board.

**Inclusion criteria:** Patients aged 18 years or older admitted to the hospital in the first 48 hours with a cancer diagnosis.



**Exclusion criteria:** Patients unable to complete survey due to impaired cognition, patients beyond the first 48 hours of admission, and patients without a cancer diagnosis.

**Study process:** Research staff and unit nurses reviewed newly-diagnosed patients to determine eligibility and potential participants. Using convenience sampling, approximately 158 eligible patients were approached, with 150 persons completing the consent process as well as the study surveys. Participants completed questionnaires in their hospital room, taking 10-20 minutes for completion. The research team was available for questions and collected completed instruments from participants. Most participants self-reported responses although the research team was available to assist participants in the case of significant fatigue or illness.

## Measures

**Distress thermometer and problem list:** The distress thermometer score and 38-item problem list were used to measure the participants' self-reported distress level and sources of distress over the past week, including the day of completion. The distress thermometer is numbered from 0 ('no distress') to 10 ('extreme distress') on a vertical thermometer image. Scores of  $\geq 4$  suggest moderate to severe distress (Rissanen et al., 2014). The distress thermometer's 38-item problem list identifies potential sources of distress, with 'yes' or 'no' answer options for each item. The range of scores is from 0-38 and comprised of five categories: practical (6 items), family (4 items), emotional (6 items), physical (21 items), and spiritual/religious (1 item).

The NCCN Distress Thermometer (DT) was utilized in a study of 291 patients preparing for bone marrow transplantation. The DT was significantly correlated (Toci et

al., 2014) with the Center for Epidemiologic Studies-Depression Scale ( $r=0.59$ ,  $P<0.0001$ ) and the State-Trait Anxiety Inventory-State ( $r=0.58$ ,  $P<0.0001$ ).

**Demographic data:** The demographic survey is comprised of data about state, county, and zip code of residence, highest level of completed education, marital status, living arrangements, number and age of dependents living in household, dependent responsibilities, household income, employment status, primary occupation, type of health insurance, current religion status, current health status, and data about primary support person.

### **Analysis**

**Sample size:** The sample size for this study was based on the sample size in a recent study of inpatient ( $n=25$ ) and outpatient ( $n=75$ ) acute leukemia and outpatient ( $n=100$ ) breast cancer survivors (Lester et al., 2013) that utilized the distress thermometer and associated problem list to measure the level and sources of distress. This study was intended to be a broad sampling of inpatients ( $N=150$ ) given the lack of published data about distress in inpatients. The potential group differences in this study could be based on disease site, metastatic or non-metastatic, or at different intervals in their cancer trajectory, e.g. newly-diagnosed, stable, progressive, or end-of-life. To begin our investigation of distress in cancer inpatients, we sought a heterogeneous sample to observe the occurrence and level of distress in various disease entities.

**Data analyses:** Descriptive statistics were used to summarize data with frequencies and percentages; when appropriate means and standard deviations were calculated. Relationships between perceived health status and distress measures were tested with analysis of variance (ANOVA). For significant findings, Tukey post hoc tests

were applied to reveal if relationships existed between perceived health status and distress. In cells with less than 5 endorsements, p-values were calculated with Fisher's exact test with a Monte Carlo approximation to the true p-value.

## **Results**

### **Sample Description**

The inpatient sample (Table 1) had a mean age group of 51-55 years of age ( $SD=2.7$ ), with a standard deviation of nearly 15 years. Most participants were white and non-Hispanic, married, and resided in Ohio. The sample was stratified for gender (e.g. 76 males and 74 females). Most participants were not working (93%); 33% reported retirement and 46% reported medical disability. Participants had a variety of primary cancer diagnoses (Table 1), including lymphoma, and breast, colon, and lung cancers. Less than 10 persons declined participation in this study with fatigue being the primary reason for declining participation.

### **Distress Levels**

Participants endorsed their level of distress on the distress thermometer, total problem list, and subscales. Overall, participants endorsed elevated distress scores (Figure 1) with a mean score of 5.8 ( $SD=2.7$ ), described as moderate to severe distress (Bogaarts et al., 2011). All distress measures were significant ( $p < 0.03$ ) with the exception of the practical scale which includes such items as housing, transportation, childcare, and insurance (Table 2).

The number of endorsements on each distress measure gradually decreased across poor to excellent levels of perceived health status. Tests of differences between distress endorsements and perceived health status (Table 2) identified significant

relationships between poor, fair, and good health status ( $p < 0.05$ ) and distress.

Exceptions include the distress thermometer and the practical subscale ( $p = 0.23$ ) and various distress scores at the excellent level ( $p > 0.08$ ).

### **Perception of Health Status**

Participants' self-reported perception of health status included poor ( $n = 46$ ), fair ( $n = 54$ ), good ( $n = 42$ ), and excellent ( $n = 3$ ); five persons did not identify their health status although did complete all measures of distress. Perceived health status was an independent covariate in 5 of 7 measures of distress. Participants with self-reported poor and fair perceived health status indicated the highest levels of distress, and conversely, good and excellent health status had lower overall distress scores (Table 2)

### **Discussion**

Distress screening is important data to incorporate into the care of cancer patients as demonstrated by the documented high levels of distress (Figure 1, Table 2) in this study. Cancer inpatients are burdened with significant distress and desire to express how they are feeling. Therefore, it is important to screen for distress, although this practice is not typically part of routine care in many institutions (Stricker et al., 2011). In our study, participants' self-reported distress was significantly ( $p < 0.3$ ) associated with perceived health status, consistent with similar studies (Baruth et al., 2014; Tonosaki, Ishikawa, 2014).

The distress thermometer was an efficient and reliable way to measure distress in this study as the instrument was user-friendly and easy to understand. The 38-item problem list was a valid method to identify the level and source of distress; however the problem list required more time and energy for completion. The increased effort

required of the 38-item problem list can be difficult for the very fatigued or ill patient.

Perhaps those patients could be screened using the thermometer and perceived health status until a more explicit screening can be obtained.

### **Distress Thermometer and Health Status**

In this study, cancer patients with numerous types of primary cancers were surveyed about their distress within the first 48 hours of admission. Participants completed the distress thermometer and associated 38-item problem list to report their level and source of distress. In addition, the participants completed a brief demographic instrument which included perceived health status (e.g. excellent, good, fair, or poor). The majority of participants ranked their health status as poor ( $n=46$ ), fair ( $n=54$ ), or good ( $n=42$ ).

Patients rated their overall distress as high ( $M=5.8$ ,  $SD=2.7$ ) within the first 48 hours of admission. Participants that reported their health status as poor were more apt to rate their distress at higher levels (Table 2). The distress thermometer itself was not significantly associated with perceived health status ( $p>0.16$ ), with the exception of the good health status category ( $p<0.01$ ). These findings are similar to a study of cancer distress in newly-diagnosed breast cancer survivors; distress was not significantly associated with stage of disease, another proxy measure of health status (Lester, et al., *in press*). As noted by the mean distress score, the majority of patients reported increased distress with the exception of the excellent category of health status ( $n=3$ ).

The concept of perceived health status should not be overlooked when processing the admission of cancer inpatients. This study found self-reported perceived health status was significantly associated ( $p>0.3$ ) with five of the seven distress

measures: 4 subscales (e.g. family, emotional, practical, and spiritual) and the total problem list, similar to findings of elevated distress by other researchers (Rissanen et al., 2014; van Houtum et al., 2013). Therefore, in a busy inpatient setting during admission procedures, the self reported level of distress *and* perceived health status may provide an approximation of the patient's distress and lead to expanded assessment and appropriate referrals as necessary. This approach may provide improved distress screening with minimum interference in admission procedures.

### **Accomplishments and Limitations**

We were successful in accruing 150 inpatients over a several month period. The vast majority of patients completed the entire instrument, providing important data for evaluation. The study was performed in a succinct time period, e.g. early admission, allowing for comparable results among participants. We sought a heterogenous sample in order to examine distress across disease entities. The study is limited to generalization as it was conducted in one institution. While the sample was evaluated for a moderate effect, a larger number of patients would need to be surveyed with data analyses prior to a practice change.

Overall, the distress thermometer is an efficient and reliable way to measure distress in cancer inpatients. The distress thermometer is user-friendly because it is quick and easy to use. The 38-item problem list is a valid and reliable instrument to identify specific stressors; however completion of this list requires additional time and effort, making it a less desirable method of screening for sources of distress. Based on this study, findings indicated that self-reported perceived health status may be a reliable indicator of elevated distress. However, these are preliminary findings; further research

is warranted to replicate results in a variety of cancer populations and ages..

### **Conclusion**

As evidenced by this study, cancer patients during early admission experience increased levels of distress independently and as associated with self-reported perceived health status. It remains imperative that health care providers screen patients for their level and source of distress. By 2015, distress screening will be required by accreditation groups for integration into practice (ACOS, COC, 2012). It would be ideal for health care providers to have several approaches to measure distress in cancer patients. Further research is indicated to determine the reliability and validity of using patient-reported perceived health status with the simple distress thermometer image to screen for distress. Professionals caring for cancer patients must screen for distress in cancer patients so that optimal health care can be provided.

### **Nursing Implications**

Registered and advanced practice nurses that care for oncology patients have a responsibility to screen their patients for the level and source of distress, with further assessment, interventions, and evaluation, as necessary. The paradigm shift of incorporating distress screening into routine care must be led by oncology nurses through education, practice change, evaluation, and future research. Nurses are integral to distress screening with assistance from the multidisciplinary team. Physicians and researchers have sought curative treatments for various cancer diagnosis, stages, and presentations. Nurses and the multidisciplinary team must lead the way to holistic care of our patients with attention to cancer and treatment-related side effects and symptoms that generate distress.

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Table 1. Types and frequency / percentage of primary cancers of hospitalized cancer patients during the first 48 hours of admission.

<b>Type of Cancer</b>	<b>Frequency</b>	<b>Percent</b>
Lymphoma	26	17
Breast	16	11
Colon / Rectal	14	9
Lung	11	7
Chronic lymphocytic leukemia	10	7
Sarcoma	10	7
Bladder / Prostate / Renal	10	7
Acute leukemia	9	6
Pancreatic / Cholangiocarcinoma / Gallbladder	8	5
Melanoma	8	5
Uterine / Ovarian / Cervical	6	4
Head & neck	6	4
Multiple myeloma	4	3
Esophageal / Gastric	4	3
Liver	3	2
Brain	2	1
Adenocarcinoma	1	1
Neuroendocrine	1	1

Significant distress scores by perceived health status in hospitalized oncology patients in the first 48 hours of admission are listed followed by means and standard deviation values of distress endorsements by perceived health status. *P*-values for tests of group differences of distress endorsements and perceived health status are subsequently noted. Superscripts (e.g.<sup>a, b</sup>) are used to identify significant differences between perceived health status and distress measures.

Table 2. Significant distress scores by perceived health status in hospitalized oncology patients.

Variable of Interest	Distress Measures						
	Distress Thermometer	Practical Subscale	Family Subscale	Emotional Subscale	Physical Subscale	Spiritual Religion Subscale	Total Problem List
<i>P</i> Values	0.002 <sup>b</sup>	0.23 <sup>a</sup>	0.03 <sup>b</sup>	0.001 <sup>b</sup>	0.00 <sup>b</sup>	0.03 <sup>b</sup>	0.00 <sup>b</sup>
Perceived Health Status	Distress Thermometer	Practical Subscale	Family Subscale	Emotional Subscale	Physical Subscale	Spiritual Religion Subscale	Total Problem List
Poor	6.9 (2.5)	1.4 (1.3)	0.9 (0.9)	3.8 (2.0)	9.3 (3.8)	0.2 (0.4)	15.6 (6.0)
Fair	5.7 (2.5)	1.1 (1.1)	0.4 (0.6)	2.6 (1.9)	6.8 (3.4)	0.1 (0.2)	10.8 (5.4)

Good	4.6 (2.9)	1.1 (1.4)	0.4 (0.7)	2.0 (2.0)	5.0 (3.4)	0.0 (0.2)	8.3 (5.4)
Excellent	5.0 (3.0)	0.0 (0.0)	0.3 (0.6)	2.3 (2.5)	4.0 (6.1)	0.0 (0.0)	6.7 (8.1)
Perceived Health Status	Distress Thermometer	Practical Subscale	Family Subscale	Emotional Subscale	Physical Subscale	Spiritual Religion Subscale	Total Problem List
Poor	0.16 <sup>a</sup>	0.64 <sup>a</sup>	0.03 <sup>b</sup>	0.02 <sup>b</sup>	0.003 <sup>b</sup>	0.0	0.00 <sup>b</sup>
Fair	0.16 <sup>a</sup>	0.64 <sup>a</sup>	0.03 <sup>b</sup>	0.02 <sup>b</sup>	0.003 <sup>b</sup>	0.03 <sup>b</sup>	0.00 <sup>b</sup>
Good	0.01 <sup>b</sup>	0.79 <sup>a</sup>	0.05 <sup>b</sup>	0.00 <sup>b</sup>	0.00 <sup>b</sup>	0.03 <sup>b</sup>	0.00 <sup>b</sup>
Excellent	0.72 <sup>a</sup>	0.3 <sup>a</sup>	0.78 <sup>a</sup>	0.74 <sup>a</sup>	0.08 <sup>a</sup>	0.76 <sup>a</sup>	0.6 <sup>a</sup>

$P < 0.05$

Superscripts represent significant differences (<sup>b</sup>) between perceived health status and distress scores, or no significant differences (<sup>a</sup>).

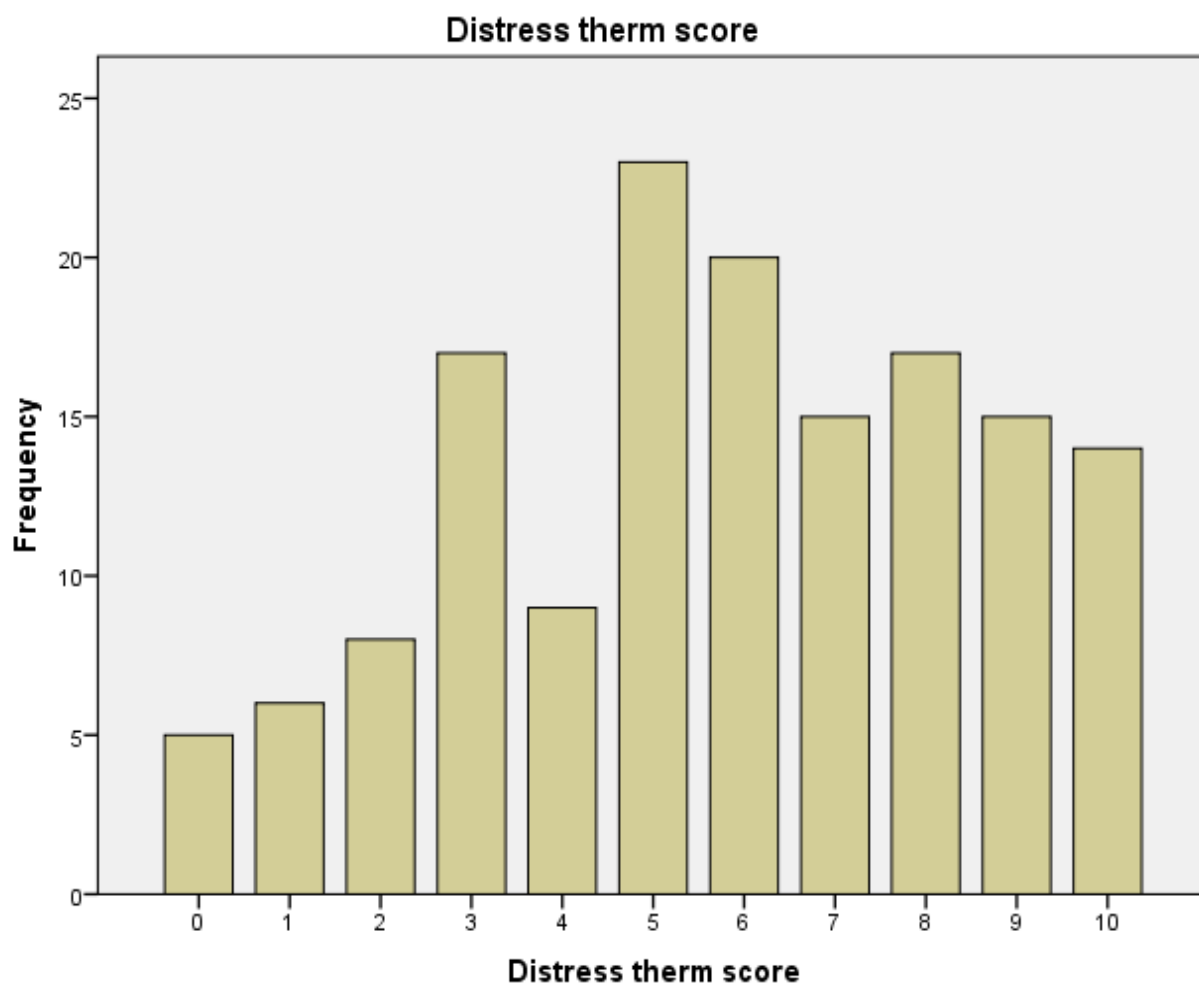


Figure 1. Ranking of self-reported distress by study participants using the distress thermometer.

